

**Assessing the State of Vaccine Confidence**

**In the United States:**

**Recommendations from the  
National Vaccine Advisory Committee**

**Draft Report: Version 2**

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DRAFT

*Every day with a child, I have discovered, is a kind of time travel. I cast my mind ahead with each decision I make, wondering what I might be giving or taking from my child in the future. I send him off to preschool, where he learns about germs and rules, wondering all the time who he might have been if he had not learned to wash his hands and stand in line as soon as he could talk. But even when I do nothing, I am aware that I am irrevocably changing the future. Time marches forward in a course that is forever altered by the fact that I did nothing.*

--Eula Biss, *On Immunity: An Inoculation* (2014)

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## Executive Summary

As 2014 ended and 2015 began, measles, a disease no longer considered endemic in the United States, was infecting dozens of people in this country and threatening to infect hundreds more. While the initial case likely was the result of measles being brought into the country, the first exposures came at a popular tourist destination, which meant it would not take long for the virus to be transmitted to other people. Thus, as January came to a close, over 80 cases of measles had been reported, with most linked to the initial cases-- and the outbreak had spread to at least fourteen U.S. states as well as Mexico.<sup>1</sup>

This latest measles outbreak provided yet another reminder of the importance of vaccines and timely vaccination. Although the source case of the outbreak is not known, the first identified case stemmed from an individual who had not been vaccinated against measles and most of the subsequent infections involved people -- who were unvaccinated.

Unfortunately, in many cases, the unvaccinated children were likely unvaccinated by choice -- recommended measles vaccination must have been delayed or declined, a choice that left the children vulnerable and the rest of the unvaccinated population, susceptible to measles. Children too young to be vaccinated, as well as children who cannot be vaccinated because of health conditions, depend on high levels of vaccination coverage for protection against infectious diseases like measles. Immunity is often silent or invisible until it is tested—and measles is one of the most sensitive “stress tests” we have.

The need to maintain the nation’s high childhood immunization rates, along with evidence that more parents are hesitating or delaying when it comes to following vaccination recommendations, prompted the Assistant Secretary for Health and Human Services to ask the National Vaccine Advisory Committee (NVAC) to assess how confidence in vaccines affects childhood vaccination in the United States. In response to this request, in February 2013, NVAC put together a Vaccine Confidence Working Group (VCWG).

This report is the result of the NVAC VCWG’s effort and examination. The effort began with development of a definition of vaccine confidence and an examination various factors that influence vaccination -- role of parents and healthcare providers, the processes involved in

vaccine development, testing, licensure, recommendations and policy, the communication environment, and perceptions of susceptibility, efficacy and safety. For the Working Group, “Vaccine Confidence refers to the trust that parents or healthcare providers have (a) in the immunizations recommended by the Advisory Committee on Immunization Practices (ACIP), (b) the provider(s) who administer(s) vaccines, and (c) the processes that lead to vaccine licensure and the recommended vaccination schedule.”

Vaccines are one of the most effective and successful public health tools to prevent disease, illness, and premature death from preventable infectious diseases. As this report illustrates, there is much good news in the U.S. when it comes to recommended vaccines and vaccinations. Vaccination rates among children are high and for most parents, following the recommended schedule is the norm. Healthcare providers are highly supportive of vaccines and immunization recommendations and for most parents, are a trusted source of information and guidance. When it comes to fostering vaccine confidence, the Working Group repeatedly heard that trust in healthcare providers, healthcare provider communication and endorsement, social norms, and communication play central roles in instilling, maintaining and fostering vaccine confidence.

The Working Group also heard about several challenges that threaten the success. As this report indicates, there are communities and places (e.g., schools) where vaccination levels are below – sometimes far below – the levels needed to protect those who are unvaccinated.<sup>2</sup> There are also parents whose reluctance, hesitation, concerns, or lack of confidence has caused them to question or forego recommended vaccines. In some cases, the children are vaccinated as recommended, but in other cases, vaccinations are delayed or declined. In these cases, the child is left susceptible to the disease and if infected, can transmit it to others.

While the Working Group learned that the Centers for Disease Control and Prevention(CDC) is continually assessing the nation’s childhood immunization coverage through the National Immunization Survey (NIS), it also learned that significant gaps exist when it comes to measuring, monitoring and tracking vaccine confidence. The NIS, for instance, does not routinely include measures related to vaccine confidence, nor is there a



standardized, validated set of questions for measuring vaccine confidence. It is also the case that whatever current efforts exist, do not account for variations at the state, local and provider levels, meaning it is not possible to gauge nor understand community-level vaccine confidence, including potential vulnerability to a vaccine preventable disease. As the VCWG also learned, it is often the case that those who delay or decline recommended vaccinations often live in close proximity to each other or send their children to the same schools. A lack of information on where such clusters exist, and the reasons behind the lack of vaccination, make these areas particularly vulnerable to vaccine preventable infectious diseases. It is thus highly recommended that investments be made in improving the nation's ability to measure and assess vaccine confidence.

As noted in this report, the end goal—achieving acceptance of all Advisory Group on Immunization Practices (ACIP) recommended vaccinations by parents and healthcare providers—will require continued and expanded efforts on multiple fronts and by multiple entities. On the science side, the initial efforts to develop a multi-national research network to advance the science to understand vaccine confidence and hesitancy needs to be sustained and extended. As the World Health Organization's Strategic Advisory Group of Experts' (SAGE) vaccine hesitancy efforts illustrate, building and fostering vaccine confidence and acceptance is not just the problem in the US but an issue of urgent importance in global health. More efforts are needed to identify, develop and evaluate strategies and approaches to find the ones that facilitate or instill confidence – and resources and systems need to be in place to share lessons learned and effective practices. Along these lines, it is also the case that vaccine confidence and acceptance efforts need to encompass healthcare providers. Not only is it imperative that they have high confidence in recommended vaccines and vaccinations, they must have the resources, capacities and capabilities needed to effectively educate and address parent questions and concerns. In most cases, it is healthcare providers who directly affect parents' confidence and acceptance of recommended vaccines and vaccinations.

The near invisibility of vaccine preventable diseases speaks to the value and success of vaccines. It also highlights the importance of constant – and greater – vigilance when it comes to vaccine confidence. In the absence of disease, for many people, it is confidence –

in the vaccine, the recommendation, the provider and the processes – that fosters their vaccine acceptance and in turn, the nation’s high immunization rates.

## **Vaccine Confidence Recommendations**

### **Focus Area 1: Measuring and Tracking Vaccine Confidence**

1.1 NVAC recommends development of an “index,” composed of a number of individual and social dimensions, to measure vaccine confidence. This index should be capable of 1) a rapid, reliable and valid surveillance of national vaccine confidence; 2) detection and identification of variations in vaccine confidence at the community level; and 3) diagnosis of the key dimensions that affect vaccine confidence.

1.2 NVAC recommends continuing the use of existing measures for vaccine confidence, including systems that measure vaccine coverage as well as vaccine-related confidence, attitudes and beliefs while the science of understanding and tracking vaccine confidence is being advanced.

1.3 NVAC recommends the development of measures and methods to analyze the mass media environment and social media conversations to identify topics of concern, to parents, healthcare providers, and members of the public.

1.4 NVAC recommends that existing approaches and systems for monitoring vaccination coverages and vaccine-related cognitions, attitudes and behaviors be strengthened and enhanced. These include: (1) Immunization Information Systems (IIS) and Electronic Health Records (EHRs) to collect and capture delays and refusals; (2) Reliable and valid measures (or surveys) of cognitive factors, such as adults and parents’ confidence, attitudes and beliefs regarding vaccines and recommended vaccinations; (3) Surveys of provider attitudes and beliefs towards vaccination; and (4) Integration of data from all existing systems to track trends of vaccination confidence over time and to detect variations across time and geography.

### **Focus Area 2: Communication and Community Strategies**

2.1 NVAC recommends healthcare providers, immunization programs, and those involved in promoting recommended vaccinations actively reinforce that vaccination according to

the ACIP recommended schedule is the social norm and not the exception. Misperceptions that vaccination in line with the ACIP recommended schedule is not the norm should be appropriately addressed.

2.2 NVAC recommends consistent communications assessment and feedback pertaining to vaccine confidence. These include:

2.2.1 Creation of a Communication Assessment Infrastructure to assess vaccine sentiment and provide timely, accurate and actionable information related to vaccination confidence and acceptance to relevant stakeholders. This system should have the capability to regularly assess vaccine-related messaging environment (e.g., to identify new or emerging concerns and questions) to assess understanding and effectiveness of population education and information materials and resources.

2.2.2 Identification, evaluation and validation of communication resources and approaches in terms of their effects on enhancing vaccine and vaccination confidence so that effective (“evidence-based/evidence-informed”) interventions and best practices can be shared and more widely used.

2.2.3 Creation of a repository of evidenced-based best practices for informing, educating and communicating with parents and others in ways that foster or increase vaccine or vaccination confidence. This repository would be maintained and expanded as future evidence is compiled regarding messages, materials, and interventions that positively affect vaccine or vaccination confidence.

2.3 NVAC recommends the development of systems to support parent and community efforts that seek to promote vaccine confidence and vaccination.

2.4 NVAC recommends support for a community of practice or network of stakeholders who are actively taking steps to foster or grow vaccine confidence and vaccination; such a network can foster partnerships and encourage sharing of resources and best practices.

### **Focus Area 3: Healthcare Provider Strategies**

3.1 NVAC recommends the development and deployment of evidence-based materials and toolkits for providers to address parent questions and concerns. These materials and toolkits should continue to be revised to incorporate the latest science and research.

3.1.1 A repository of evidence-based effective practices for providers should be an output of this effort.

3.2 NVAC recommends curriculum and communication training that focuses on vaccine confidence (e.g., strategies and approaches for establishing or building confidence) be developed and made available for healthcare providers, including doctors, nurses, alternative providers and ancillary care providers.

3.2.1 This training should encompass “providers-in-training,” such as students, residents and interns as well as currently practicing physicians, nurses and other healthcare providers through Continuing Medical Education (CMEs).

3.2.2 Clear and accessible information on vaccinations, the schedule and any changes to the immunization schedule should be developed specifically for providers and made available to them through resources they utilize most.

3.3 NVAC recommends the development of: (i) Provisional billing codes for vaccine counseling when vaccination is ultimately not given; and (ii) Pay for performance initiatives and incentives as measured by: (a) Establishment of an immunizing standard within a practice; and (b) Continued improvement in immunization coverage rates within a provider’s practice.

### **Focus Area 4: Policy Strategies**

4.1 NVAC recommends states and territories with existing personal belief exemption policies should assess their policies to assure that exemptions are only available after appropriate parent education and acknowledgement of the associated risks of not vaccinating, to their child and community. Policies that do not do this should be strengthened.

4.1.1 Increased efforts should be made to educate the public and state legislatures on the safety and value of vaccines, the importance of recommended vaccinations and the ACIP schedule, and the risks posed by low or under-vaccination in communities and schools.

4.2 NVAC recommends information on vaccination rates, vaccination exemptions and other preventative health measures (e.g., whether a school has a school nurse, etc.) for an educational institution be made available to parents.

4.2.1 Encourage educational institutions and childcare facilities to report vaccination rates publicly (e.g., via a school health grade or report).

4.3 NVAC recommends “on-time vaccination” should be included as a Quality Measure for all health plans, public and private as a first line indicator of vaccine confidence. NVAC acknowledges that other issues, such as access, can also effect on time vaccination.

### **Final Recommendation**

5.1 The NVAC recommends that the National Vaccine Program Office (NVPO) should work with federal and non-federal partners to develop an implementation plan to address vaccine confidence, including metrics, and report back to NVAC on progress, annually.

## Introduction

Vaccines are among the most effective public health interventions available, saving between 2 and 3 million lives per year around the world.<sup>3</sup> Most vaccines in use today provide high levels of individual protection against disease. In addition, most vaccine-preventable diseases are spread from infected persons to susceptible persons. When there are high levels of immunity in a community induced by vaccination, a transmitting case is unlikely to encounter a susceptible host, thus terminating transmission and preventing exposure of others in the community who are either not protected by vaccination (no vaccine is 100% effective<sup>4</sup>), cannot be vaccinated (i.e., have a legitimate contraindication to vaccination), or persons who are not eligible for vaccination (e.g., children too young for some recommended vaccines). Thus, what makes vaccines unique is that with high levels of vaccination both the individual and the community are protected, a phenomenon, characterized often as “herd immunity.” However, high vaccination coverage rates are required for community protection. In the United States, high vaccination rates have been reached for many recommended vaccines, leading to the near elimination of the corresponding Vaccine Preventable Diseases (VPDs) and 99-100 percent reductions in VPD mortality – leading to thousands of lives saved each year.<sup>5</sup> While this speaks to the great success of vaccines and the efforts of all the stakeholders involved in vaccination programs in the United States, there is still work to be done. Not all recommended vaccinations have reached high coverage rates and there are pockets of the country where coverage is not high enough to achieve population protection, leaving the public vulnerable to disease outbreaks.

One significant factor to achieving and maintaining the high vaccination rates needed to sustain community-level protection against VPDs is high public confidence in vaccinations. Vaccination confidence, or the level and amount of trust that people have in recommended vaccines and those who administer vaccinations, is often a significant determinant of vaccine acceptance. When confidence is high, people will likely support immunization recommendations and follow recommended schedules. When confidence is low or lacking, people are more likely to hesitate and may decide to delay or forego recommended vaccinations. The recognition of the need to support public confidence in vaccinations is

growing and has become a focus for public health organizations in the U.S. and internationally. For example, the World Health Organization's Strategic Advisory Group of Experts (SAGE) on Immunization formed a committee on Vaccine Hesitancy which, in its report to SAGE, called for concerted action to stem hesitancy in certain parts of the world.

Despite these important concerns, it should be noted that vaccination in accordance with the Centers for Disease Control and Prevention's (CDC) Advisory Committee on Immunization Practices (ACIP) Recommended Immunization Schedule continues to be the social norm for children and high vaccination coverage of children has been achieved for most recommended vaccines on the recommended immunization schedule. For infant and early childhood immunizations, rates have been high and stable for the past several decades – at or above the 80-90 percent range for nearly all ACIP recommended childhood vaccinations.<sup>6,7</sup>

Similarly, recent reports suggest that a majority of parents have favorable beliefs or perceptions in regard to vaccines. A 2009 HealthStyles survey of parents of children 6 years old and younger, for instance, found 79 percent were “confident” or “very confident” in the safety of routine childhood vaccines. A 2010 HealthStyles survey found 72 percent of parents were confident in the safety of vaccines, with slightly more parents expressing confidence in the effectiveness of vaccines (78 percent) and the benefits of vaccines (77 percent). Further analyses of these data showed that, two factors -- confidence in vaccine safety and confidence in vaccine effectiveness –are a major source of influence on parents' self-reported vaccination behavior.<sup>8</sup> Overall, however, these studies also suggested that about one in five parents were not fully confident in the safety or importance of recommended vaccinations. The Cultural Cognition Project at the Yale Law School has collected data involving or related to confidence. They found, for instance, that about 27 percent of adults strongly to slightly disagree with the statement “I am confident in the judgment of public health officials who are responsible for identifying generally recommended childhood vaccinations.” About 62% had moderately or extremely high confidence in “the judgment of the American Academy of Pediatrics that vaccines are a safe and effective way to prevent serious disease” but about 20 percent had relatively low confidence.<sup>9</sup>

National estimates, however, can mask local geographical variation in coverage rates. In other words, there are pockets of the country with particularly low vaccination coverage that is overshadowed by strong national rates.<sup>10</sup> While most parents choose to vaccinate their children according to the Advisory Committee on Immunization Practice (ACIP) recommendations, as with any medical decision parents make for their children, they may have questions or concerns about immunization decisions. More critical, there are reports suggesting that some parents are choosing to delay and/or refuse one or more recommended vaccines. There is also evidence that some parents are following alternative schedules, indicating they may have concerns about the ACIP recommended schedule.<sup>11-14</sup> Finally, exemptions obtained for personal reasons from school immunization requirements have been increasing in some school districts and states.<sup>15,16</sup> Delays and refusals of recommended vaccinations provide evidence that some parents lack confidence in recommended vaccines. Delays and refusals also are concerning because they leave children and communities vulnerable to disease outbreaks. In the U.S., measles is one illustration of this vulnerability. In the past several years, measles outbreaks have occurred in communities and schools which had “pockets” of un-immunized people or children.<sup>17</sup>

In response to concerns that vaccination acceptance is not as high as needed to achieve optimal use of all ACIP recommended vaccinations, and in an effort to better understand how best to foster confidence to achieve and sustain high vaccination rates, the Assistant Secretary for Health (ASH) asked the National Vaccine Advisory Committee (NVAC) to form a Vaccine Confidence Working Group (VCWG) in February 2013.

### **Charge to the Working Group**

Recognizing that immunizations are given across the lifespan and there are likely to be important differences in vaccine acceptance at different stages of life, the Assistant Secretary for Health (ASH) is initially charging the National Vaccine Advisory Committee (NVAC) to report on how confidence in vaccines impacts the optimal use of recommended childhood vaccines in the United States, including reaching HP2020 immunization coverage targets. Focus of such a report may include understanding the determinants of vaccination acceptance among parents, what HHS should be doing to improve parental confidence in



vaccine recommendations and how to best measure confidence in vaccines and vaccination to inform and evaluate interventions in the future.

In response to the Charge from the ASH, the VCWG set out to first define vaccine confidence and its constituent factors and to understand the state of vaccination confidence in the United States. From this framework, the VCWG formulated recommendations related to identifying, measuring and tracking vaccine confidence moving forward. Finally, the group recommended strategies and approaches for sustaining and increasing parental confidence in vaccines, including research to identify ways to strengthen confidence.

### **Working Group Membership**

Working Group membership was limited to members and liaison members of NVAC as listed in Appendix A. In the process of developing this report and recommendations, the Working Group solicited extensive input from experts in this field as well as from a range of stakeholders, including providers, public health practitioners, policy makers, and parents with young children. The agenda of presentations and presenters is listed in Appendix B. This report summarizes the information and perspectives considered by the Working Group, and summarizes the Working Group's findings, conclusions and recommendations. Each of the sections that follow focuses on a major component of the Working Group's effort.

## **Key Terms and Definitions: Vaccine Acceptance and Confidence**

### **Introduction and Overview**

One of the first objectives of the NVAC VCWG was to agree on consistent, clear, and measurable definitions for the key terms and concepts encompassing vaccination decision-making. Currently in the literature, the terms “hesitancy,” “confidence,” “trust,” and “acceptance” have been used, sometimes interchangeably, to describe the factors that influence an individual’s decision to accept recommended vaccinations as well as society’s overall level of support of vaccination<sup>18-21</sup>. This conflation of different terms could make it difficult to document, track and intervene on confidence.

It is important to note that numerous factors influence whether a recommended vaccine is accepted, including knowledge of the recommendation, availability of vaccination services, vaccine affordability, and accessibility. However, the focus of the VCWG’s efforts was to understand the drivers of individuals’ or parents’ decisions to accept immunizations when safe and effective vaccines are recommended and high-quality vaccination services are available. That is, all things being equal, what are the major individual and social determinants influencing the confidence in recommended vaccines?

There is consensus that attitudes and intentions with regard to vaccination fall along a continuum that ranges from complete refusal to complete acceptance of all recommended vaccines, administered at the recommended times.<sup>22-24</sup> The terms above, particularly hesitancy and confidence, have been used in the literature to describe those individuals who fall in the middle of this continuum. The individuals and parents in the middle are a heterogeneous group whose attitudes and intentions with respect to vaccines vary. Some of them delay or refuse some recommended vaccines as a result of their concerns, while others get recommended vaccinations for themselves or their children despite having concerns.

While the NVAC VCWG recognizes that much remains to be learned regarding the scale, scope and details of vaccine confidence in the United States, it concluded that fostering acceptance of all ACIP recommended vaccines administered at the recommended ages should be the end goal. With childhood vaccinations in mind, the VCWG chose to focus on

vaccine and vaccination confidence of parents. In addition, the VCWG concluded the focus should be on building the confidence of those in the middle of the continuum to promote acceptance.

### **Confidence vs. Hesitancy**

The NVAC Working Group chose to focus attention on “vaccine confidence” rather than “vaccine hesitancy” for three reasons. First, in reviewing relevant literature, conversations with other stakeholders and presentations to the VCWG, it became evident that the best and most appropriate goal for immunization programs was to instill, build, and maintain high confidence in vaccines and recommended vaccinations. The positive frame of “confidence” rather than “lack of hesitancy” best characterizes how parents, healthcare providers and others should come to perceive vaccines and recommended vaccinations. Second, confidence was seen to encompass hesitancy. For example, if parents have high confidence in recommended vaccines and vaccinations, there should be little or no hesitation when it comes to having their children receive immunizations at the recommended ages. Conversely, if confidence is low or lacking, parents will likely hesitate when it comes to a recommended vaccination. Finally, the VCWG recognized that many parents have questions or potential concerns when it comes to medical decisions, including vaccinations<sup>8</sup>. The VCWG wanted to stress that questions as well as the involvement of parents in medical decisions should be respected and supported. Therefore efforts to address parents and others who have doubts and concerns should focus less on labels (e.g., ‘vaccine hesitant’) and more on how best to build and maintain confidence. The VCWG concluded it was the responsibility of the public health and healthcare provider communities to understand what was required to increase parent and public confidence in recommended vaccines and vaccinations.

### **Key Definitions**

In line with the above, the VCWG defined vaccine acceptance and confidence as:

*Vaccine Acceptance* is defined as the timely receipt of all childhood vaccines as recommended by Centers for Disease Control and Prevention’s Advisory Committee on Immunization Practice (ACIP) when vaccines and vaccine services are available.

*Vaccine Confidence* refers to the trust that parents or healthcare providers have (a) in the recommended immunizations, (b) the provider(s) who administers vaccines, and (c) the process that leads to vaccine licensure and the recommended vaccination schedule.

These dimensions assume parents are aware of the recommended vaccinations and have knowledge of how vaccination recommendations are made. These concepts are inter-related and linked, with vaccine acceptance being the desired end outcome, and vaccine confidence as an important antecedent to that outcome.

## **Vaccine Confidence-related Research**

### **Determinants of Confidence**

Vaccine confidence is a relatively new concept when it comes to understanding vaccine acceptance, but through several published review articles, presentations from experts and conversation with parents, the VCWG was able to identify and describe key determinants associated with parental confidence in, and acceptance of, childhood vaccines<sup>25-31</sup>. While it is clear that the most influential factors often differ across locations, time and individual vaccines, four factors are notable: 1) trust; 2) attitudes and beliefs; 3) healthcare provider confidence both in vaccines and their ability to communicate effectively to parents about vaccines; and 4) the information environment regarding vaccines.

In summarizing these key determinants of vaccination confidence, the VCWG hopes to

- identify potentially important factors for those studying and intervening to increase public confidence in vaccinations
- recommend methods to track confidence over time
- suggest ways to support efforts to increase and maintain the confidence individuals and communities have in vaccinations.

### **Trust**

Trust is one of the most important factors associated with vaccine confidence. Trust is the willingness to rely on someone else's expertise and advice (e.g., their vaccine recommendation). For vaccinations, trust comes into play in a number of ways and with respect to a number of stakeholders. For example, parents need to have trust in the

pharmaceutical companies that produce vaccines, trust in the healthcare system that delivers them, trust in the healthcare providers that recommend and administer vaccines, and trust in the organizations and policymakers that decide which vaccines are needed and when. Trust also extends to the safety and effectiveness of vaccines, including a belief that the system has adequately evaluated the safety and effectiveness of recommended vaccines. The level of trust parents have in government, the healthcare system and their healthcare providers are often associated with their ultimate decision to accept or refuse vaccinations for their children.

Many studies have found that trust in healthcare providers remains high among parents. A 2009 HealthStyles survey, for instance, found that around 82 percent of parents said their child's doctor or nurse were the most important source that helped them make decisions about vaccinating their youngest child.<sup>32</sup> Further, provider recommendations for vaccinations are the most commonly cited reason for vaccine confidence and ultimately acceptance, underscoring the importance of maintaining the currently high levels of parent and patient trust in individual healthcare providers.

### **Attitudes and Beliefs**

Vaccination confidence is also associated with the attitudes and beliefs that parents have regarding vaccine preventable diseases, vaccine safety, vaccine effectiveness and benefits of vaccination. It has been found that a parent's perception of their child's susceptibility to a vaccine preventable disease, their perception of the disease's severity, and their perceptions regarding the benefits, safety, and efficacy of vaccines, matter when it comes to accepting an immunization recommendation. In general, parents have more confidence in their decisions to follow the recommended vaccination schedule when they perceive that their child is likely to be struck by a disease (susceptibility), that the disease has serious consequences to their child (severity) and that the recommended vaccine is safe and effective (efficacy).<sup>33,34</sup>

In addition, parent attitudes and confidence in vaccination are strongly influenced by perceived social norms. Social norms refer to the perceptions that people hold in respect to the views and actions of others who are significant in their reference group or are their role

models. In the case of vaccination, parents may try to gauge what the majority of parents are doing or what other parents they know are doing (e.g., are most following the recommended schedule?). With respect to vaccine confidence, parents are more likely to be confident in immunization recommendations if they perceive others in their social group have high levels of vaccine acceptance. Conversely, the perceptions that other parents in their circle are delaying or declining recommended vaccinations can lower parental confidence in vaccines. News media stories, and how they frame the value, safety and effectiveness of vaccinations, can also contribute to parent perceptions of social norms.

Social norms also can exert influence on the cognitive heuristics that people often use when making medical and health-related decisions, including those involving immunizations. Cognitive heuristics are decision-making shortcuts used to either quicken the decision-making process or to make a decision. If people in a social network have experienced or are discussing the seriousness of a vaccine preventable disease, the disease is more immediately recallable and parents may be more confident in decisions to vaccinate because of that awareness. Conversely, if social networks are discussing vaccine reactions or possible reactions, the reverse can be more likely. Similarly, if parents perceive that most parents in their social network have confidence in vaccinations, this will in turn support their own confidence and choice to accept vaccinations.

### **Healthcare Provider Confidence**

It is clear from published studies and presentations to the VCWG that healthcare providers – the frontline people who interact with parents and who administer vaccines – are critically important when it comes to vaccine confidence. Studies consistently find that the vast majority of parents (80 percent or more) look to their child’s healthcare provider for information and advice on vaccine preventable diseases, vaccines and the recommended immunization schedule.<sup>35</sup> When providers are able to effectively communicate with parents about vaccine benefits and risks, the value and need for vaccinations, and vaccine safety, parents are more confident in their decision to adhere to the recommended schedule. From the perspective of vaccine confidence, it is thus important to note that healthcare providers are key players when it comes to establishing, maintaining and building parent confidence in vaccines. For this reason, it is critical to assess and support

healthcare providers' vaccine-related confidence as well as to equip them with the information and resources they need to confidently engage with parents in vaccine conversations. The VCWG recognizes that these efforts to support providers are critical to building and fostering confidence in the patients they serve.

### **Information Environment**

In addition to health care providers and members of their social networks, media play a critical role in influencing knowledge, beliefs and behaviors associated with vaccines. Routine media coverage of celebrities declining vaccines or questioning the safety of vaccines perpetuates the perception that vaccines are unsafe and that such beliefs are widely shared. The media's attempt to remain fair and balanced often results in the interviewing of individuals on both sides of the vaccine issue. However, anecdotal stories of perceived harm due to vaccines should not be weighed equally with the scientific evidence that said vaccine has been proven to be safe. In other words, scientists or medical professionals with impeccable credentials are often juxtaposed against a parent who is certain that vaccines caused harm when in fact the weight of the evidence counters such claims. Negative stories and misstatement of facts on vaccines, even when contradicted, remain in people's minds.

The media's influence in setting the agenda and framing the issue is further reinforced by platforms associated with new information and communication technologies (ICTs), such as social media. Social media platforms can become virtual echo chambers for fostering questions about vaccine safety and reinforce false information and myths. The VCWG recognizes the important role news, entertainment and social media play as situational determinants driving vaccine confidence.

## **Vaccine Acceptance and Confidence in the U.S.**

### **Introduction and Overview**

This section summarizes the current data on childhood vaccination coverage in the U.S., along with 1) available information related to deviations from the recommended immunization schedule (e.g., immunization delay or declination); 2) information on exemptions from school immunization requirements; and 3) some key findings from surveys of parent attitudes and beliefs and confidence with regard to childhood immunizations. At present, this type of information represents the best available data on vaccine acceptance and confidence in the United States. In addition, this section describes some of the perspectives of providers, parents, and public health workers that have been collected through VCWG deliberations. Combined, the available data and information provide an instructive overview of the overall state of vaccine acceptance and confidence in the U.S., as well as insights into the ways a lack of confidence can affect parent acceptance of immunization recommendations.

### **National Coverage Data**

National vaccination coverage data collected and reported by the CDC suggests that parental acceptance of vaccines and vaccination recommendations are quite high. Over the past decade, data from the CDC's National Immunization Survey (NIS) show consistently high and stable vaccination rates among children 18-35 months of age. The percentage of children who received no vaccinations has also remained consistently below 1.0 percent (0.7 percent) over the past decade.<sup>6,7</sup>

Healthy People 2020 (HP2020), the nation's 10-year strategic plan for improving the health of all Americans, sets a target of 90 percent coverage for 1 dose of measles mumps and rubella vaccine (MMR), 3 doses of poliovirus vaccine, 3 doses of hepatitis B vaccine (HepB), 1 dose of varicella vaccine, 4 doses of diphtheria, tetanus, and acellular pertussis vaccine (DTaP), 4 doses of pneumococcal conjugate vaccine (PCV), and the full Haemophilus influenza type b vaccine (Hib) series. In 2013, coverage was at or above the HP2020 target for MMR, polio, HepB and varicella. Coverage was below the HP 2020 targets for  $\geq 4$  doses of diphtheria, tetanus, and acellular pertussis vaccine (DTaP) (83.1 percent; target 90 percent);  $\geq 4$  doses of pneumococcal conjugate vaccine (PCV) (82.0 percent; target 90



percent); the full series of Haemophilus influenzae type b vaccine (Hib) (82.0 percent; target 90 percent);  $\geq 2$  doses of hepatitis A vaccine (HepA) (54.7 percent; target 85 percent); rotavirus vaccine (72.6 percent; target 80 percent); and the HepB birth dose (74.2 percent; target 85 percent). HepA and rotavirus vaccines were the most recent additions to the childhood immunization schedule and coverage rates have been increasing since their incorporation, but remain below the rates of the other vaccinations. Children living below the federal poverty level had lower vaccination coverage compared with children living at or above the federal poverty level for many vaccines, with the largest disparities for  $\geq 4$  doses of DTaP (by 8.2 percentage points), full series of Hib (by 9.5 percentage points),  $\geq 4$  doses of PCV (by 11.6 percentage points), and rotavirus (by 12.6 percentage points).<sup>7</sup>

### **State Coverage Data**

State vaccination coverage rates reveal a more nuanced and variable picture that is masked by the national coverage averages. In general, state coverage rates have also remained stable for the past decade. However, the most recent CDC coverage data continues to demonstrate wide geographic variation in vaccination coverage among the states in 2013.<sup>7</sup> Specifically, the 2013 data showed the combined childhood vaccine series (MMR, polio, HepB, varicella, DTaP, PCV and Hib) coverage estimates ranged from 60.6 percent in Nevada to 82.1 percent in Rhode Island. Looking at individual vaccines, using MMR as an example, Colorado and Ohio had the lowest coverage at 86.0 percent and New Hampshire with the highest at 96.3 percent. Overall, MMR coverage was below 90 percent in 17 states.<sup>7</sup>

In summary, two themes emerge from the national and state coverage data. First, at both a national and state level, vaccine acceptance has remained high and stable over the past decade; though uptake is relatively slow for newly recommended immunizations (e.g., rotavirus vaccine) or expanded immunization recommendations (e.g., influenza vaccine). Second, national data especially, but also state data, mask variation in coverage at local levels, where exemption data and other reports indicate lower coverage rates in some places. Thus, when it comes to vaccine acceptance, the available national and state level data indicate that immunization rates vary by both geography (e.g., state, community,

school district) and by vaccine. This variation in vaccine acceptance, both by location and by vaccine, demonstrates the importance of assessing and accounting for variation at the local level to understand which specific vaccine coverage targets are not being met and why (including issues of confidence, access, and others).<sup>36</sup>

### **Day Care and School Exemptions**

School and day care exemption-related data have been used to help assess vaccination acceptance at a more granular level. In the U.S., day care and school immunization requirements are the responsibility of states and nearly all states require children to receive most of the ACIP recommended childhood immunizations before entering day care and/or kindergarten. All states allow exemptions from vaccination requirements for medical contraindications and in 48 states parents can also obtain religious or philosophical exemptions, including personal belief exemptions. Although state and local school district exemption data are not completely standardized, they can and have been used to identify schools or communities where relatively high numbers of children have vaccination exemptions. As such, exemption rates can be used to identify places where vaccination acceptance is lagging, decreasing or changing and as one indicator of levels of or changes in vaccine confidence.

Rates for religious and philosophical exemptions increased between 1991 and 2004, from 0.98 to 1.48 percent. Looking only at states with philosophical exemptions, the increase is more pronounced; from 0.99 to 2.54 percent and the exemption rates are higher in states that make it easier for parents to obtain exemptions.<sup>16,36,37</sup> Further, while average state-level exemption rates are low, there is evidence for geographic clustering of “exemptors.” For example, in Washington State the overall exemption rate in 2006 was 6 percent, but county level exemption rates ranged from 1.2 to 26.9 percent.<sup>36</sup> Counties with high exemption rates are at much higher risk of VPD outbreaks. For example, school exemption data show a clear association between clusters of exemptions and increased incidence of pertussis.<sup>37</sup>

However, some cautions about using school exemptions have been raised. Salmon and colleagues<sup>38</sup> found, for instance, that 22 percent of the children who had been identified as “exemptors” by their schools were in fact fully vaccinated. Salmon et al. also found that

there was a high proportion of children with exemptions to only certain vaccines (75.5 percent), highlighting that exemption data often do not provide information on which specific vaccines or how many were exempted. Overall, it appears that school exemption data have value for identifying schools or communities where vaccine confidence and acceptance may be lagging, but it is also important to assess the completeness and quality of the data before drawing conclusions.

### **Delays and Alternative Schedules**

While the CDC's National Immunization Survey (NIS) is designed to provide timely and accurate national and state vaccination coverage data, the NIS is not currently designed to provide information about intentional vaccination delays or refusals on a regular basis. Obtaining information on intentional delays or refusals requires adding questions to the standard survey. Data from two instances in which this was done suggest slightly more parents may be delaying recommended vaccinations and that the percentage has also slightly increased. NIS data showed 21.8 percent of parents delayed 1 or more vaccines in 2003,<sup>39</sup> which increased to 25.8 percent by 2009.<sup>12</sup>

The NVAC VCWG also found that there were a number of relatively recent studies showed that between 10 and 25 percent of parents have delayed or may be delaying recommended vaccines or deviating from the ACIP recommended schedule. A national survey, conducted in 2013 and addressing vaccine refusals, reported that most pediatricians (87%) had parents request an alternative vaccine schedule (AVS) and estimate that 16% of parents asked for an AVS for at least one vaccine during the past year.<sup>40</sup> A national survey in 2010 found that 13 percent of parents reported using an alternative vaccination schedule.<sup>41</sup> In a national survey of physicians, conducted in 2012, 93% reported that some parents of patients with children younger than two years requested to spread out vaccines in a typical month. Despite concerns about spreading out recommended vaccinations for their young patients, 82% of the physicians in the survey believed that honoring these requests would build trust with the families.<sup>42</sup> In Colorado, a study of Kaiser Permanente members found that approximately 49 percent of children in the study population were under-vaccinated for at least 1 day from 2004-2008. This number increased from 41.8 percent in 2004 to 54.4 percent in 2008. This study further estimated that 13 percent of

children were under-vaccinated due to parental choice from 2004-2008, which is consistent with the national estimates.<sup>43</sup> In addition, a study from Portland, Oregon showed the percentage of parents choosing to limit the number of vaccinations received per visit increased from 19.0 percent in 2005 to 30.1 percent in 2009.<sup>44</sup> .

As the Portland data show, national or state level findings do not provide information or insights into the vaccine-related decision making of parents in a given community, where changes to the recommended immunization schedule may be happening more often. These data do indicate that despite relatively high and steady national coverage rates, there are also parents choosing to delay or decline recommended vaccines in different pockets of the country.

### **Surveys of Confidence, Attitudes and Beliefs**

As previously noted, there is likely a relationship between attitudes and beliefs and vaccine confidence. Parent confidence in vaccines and vaccination recommendations, is often linked or influenced by their beliefs as well as whether they have favorable or unfavorable perceptions when it comes to such things as vaccine safety, effectiveness and value. It is likely the case that there are a variety of attitudes and beliefs that may influence parents' confidence in vaccines, and in turn, their willingness to adhere to the ACIP recommended schedule. For instance, in one systematic review of 15 studies using various qualitative methods, the authors found that many parents believed that vaccines caused adverse health events, and expressed concerns specific to short- and long-term adverse events.<sup>30</sup> The authors also found that some parents expressed a substantial level of distrust of the medical community, and identified several challenges with access, including poor communication with health care staff, unpleasant staff, and being unaware of the current, approved vaccination schedule.<sup>30</sup>

### **Pediatrician and Provider Perspectives**

A healthcare provider's interaction with a parent often greatly impacts decisions to accept vaccinations and follow the ACIP recommended immunization schedule. In most cases, parents rely on their child's healthcare provider for information and advice, and the healthcare providers' knowledge, approach, and communication skills are the most influential determinants of parents' vaccination-related behaviors.<sup>45</sup> In surveys of parents,

healthcare providers are consistently listed as the most trusted source of information.<sup>46</sup> In addition, parents who changed their minds with respect to vaccination (e.g., deciding to vaccinate on time rather than delay) often cite a provider recommendation as the reason for the change. The provider-parent interaction when it comes to vaccines may be even more predictive of vaccination status than parent demographic characteristics.<sup>45</sup>

While the majority of healthcare providers (84 percent) feel comfortable addressing parent's questions and concerns regarding vaccines, most also believe parents' confidence in vaccines is declining and more parents are requesting alternative vaccination schedules. A national survey of providers in 2009 found that 43 percent of providers thought parents' level of concern had greatly increased and 28 percent thought it had moderately increased compared to an earlier time period.<sup>47</sup> This same survey reported that in a typical month 79 percent of providers had at least one parent refuse a vaccine, 89 percent had at least one request to spread out vaccines, and 20 percent reported that more than 10 percent of parents requested to alter the vaccine schedule.<sup>47</sup> Similarly, the American Academy of Pediatrics reports that up to 85 percent of physicians encounter families or parents who are planning to refuse one or more recommended vaccines.<sup>48</sup> Healthcare providers also report challenges when communicating about vaccines with parents. Time constraints on increasingly extended providers, lack of information regarding new vaccines and vaccination recommendations and safety, and parents' having misperceptions or misinformation regarding vaccine safety or adverse events have all been cited as challenges by providers.<sup>47,49</sup>

In summary, even though adherence to recommendations is the norm, from the provider perspective, more parents have concerns and more are requesting alterations to the recommended immunization schedule. Due to the importance of provider-parent relationships in fostering vaccination confidence and acceptance, the VCWG noted the necessity in efforts to support physicians, nurses and other clinicians in their roles as vaccine educators. To do so, it will be important to more frequently survey providers to understand the barriers they face, and to develop and promote tools that will assist them in providing vaccine-related education and counseling.

## **Public Health Perspectives**

There is a general sense from state immunization program managers that parent confidence in vaccines is in decline in some communities along with an increase in the number of parents using alternative vaccination schedules. According to a survey of state immunization managers conducted in January 2014, most listed vaccine hesitancy as a moderate to high priority for their programs. According to state immunization managers, areas with low vaccination confidence are normally identified through increases in school exemptions and/or from conversations with local healthcare providers. Few immunization program managers relied on immunization registry data or coverage rates, and in fact, most listed the lack of local information and coverage data as barriers to precisely gauging the state of vaccine acceptance and/or identifying communities of hesitant parents and their specific concerns. Lack of resources to collect local coverage data as well as assess parents' concerns was also cited as a barrier.

## **Conversation with Mothers on Vaccine Confidence**

As the studies previously referenced illustrate, parents fall along a spectrum with respect to vaccination attitudes and beliefs. In addition to reviewing recently published research, the VCWG elicited input from 11 mothers and 1 mother-to-be via three on-line focus groups. The focus groups included mothers who were following the ACIP recommended immunization schedule as well as mothers who had or planned to delay or decline some recommended vaccinations. The focus group discussions were designed to obtain participants' thoughts regarding recommended vaccinations, perceptions of vaccinations, and suggestions for increasing parents' confidence in recommended vaccinations.

The themes that emerged from these discussions reinforced the findings from the literature. First, all the focus group participants were seeking to make the best decisions for their child(ren)'s health when it came to vaccinations, including the mothers who had or were planning to delay or forego recommended vaccinations. Most of the mothers indicated that they had done some "research" related to vaccines and vaccination (e.g., Internet searches) as well as talked with their child's healthcare provider. Second, confidence in recommended vaccines and vaccinations varied, with mothers who were following the ACIP recommended schedule having the most confidence. Mothers who

expressed less confidence noted they had questions or concerns regarding the number of vaccinations given at one visit, the timing of vaccinations and/or about specific vaccines (e.g., flu, HPV). Third, most of the mothers indicated that it was important for parents to be educated about vaccines and to be active participants when it came to vaccinations. Many, for instance, noted that parents should do their own research and ask healthcare providers questions about vaccines. This point goes hand-in-hand with another theme from the focus group discussions; parents want to be viewed and treated as individuals by healthcare providers – as one mother noted: “First and foremost, knowing my physician is listening to my concerns (is important) whether or not they already know they are right- to see me and my child as unique human beings with unique concerns.” Finally, with respect to steps that could be taken to foster vaccine confidence, suggestions included: providing more information on how vaccines work in a child’s body; encouraging strong partnerships between parents and healthcare providers; sharing more research related to vaccine safety, as well as providing greater visibility of what’s been learned regarding vaccine safety; and efforts to address and/or accommodate parent preferences regarding the vaccination schedule.

### **Conclusions on the State of Vaccine Acceptance and Confidence in the U.S.**

From the data and perspectives gathered, the VCWG concluded that vaccine acceptance remains high and stable for the majority of infant and childhood vaccines in the U.S. However, vaccine confidence may not be as high as needed for all recommended vaccinations or as high as needed in some communities and schools. Data on school exemptions and vaccination delays and declinations as well as perspectives of parents, healthcare providers and public health workers indicate room for improvement in building confidence in order to maintain the currently high vaccination coverage rates.

## Measuring and Tracking Vaccination Confidence

### Introduction and Overview

As detailed in the previous section, there is a need for a more systematic approach to measure and track vaccination acceptance and confidence at the national, state and community levels in the United States. While our current system does show that vaccination coverage rates remain high nationally and that the majority of parents and the population support vaccinations, there are gaps in immunization programs' ability to identify specific places or communities where confidence or acceptance is low and/or may be declining. Further, the current system is often not sensitive enough to detect whether significant numbers of parents are delaying or making other changes with respect to following the ACIP immunization schedule. Information is also lacking not only at the local level, but also with respect to identifying the factors that contribute to lower immunization rates. For example, in addition to factors such as vaccination confidence, vaccination coverage is also affected by vaccine availability, access and/or affordability. State and local immunization programs often utilize school exemption information as well communication with local providers to develop a broader understanding of the local factors that may contribute to increased exemptions within communities. Although important and helpful, reliance on such information also highlights the general lack of consistent and accurate indicators of parent acceptance and confidence.

In addition to having more and robust measures of vaccination acceptance, the development of validated measures and consistent measurement systems for assessing vaccination confidence are needed. While some work has been done to develop and evaluate accurate measures of parent vaccination confidence, these efforts are in the early stages. Efforts to date are focused on identifying and incorporating items that encompass the major determinants or mediators of vaccination confidence, yet agreement or consensus on what the measures should include in order to link confidence to acceptance, and vaccination, is lacking. Thus, at present, there are no widely validated measures of parent or immunization provider vaccine confidence, nor have there been large-scale efforts to assess the utility of potential measures in broad parent or healthcare provider populations.<sup>50,51</sup> For vaccine confidence measures to be of value, they must not only be



linked to vaccination acceptance, they must be able to discern the elements associated with increased or decreased confidence. The availability of validated measures will also make it possible to test the effectiveness of intervention strategies designed to increase vaccine confidence and to compare intervention strategies in order to determine best practices.

### **Vaccination Confidence: Current Measurement Approaches**

There have been a number of efforts, in the U.S., Australia, and Europe to develop validated measures of vaccine confidence and to assess the level of vaccine confidence in a specified population or sub-population. Measures and approaches that were presented to the Working Group included:

- University of Sydney, Australia: Julie Leask presented to the Working Group her team's efforts to develop and evaluate a three-tiered measurement system called the 'Vaccine Attitudes Beliefs and Concerns (V-ABC). V-ABC is designed to: 1) measure and track population-level vaccine acceptance; 2) identify – for either individuals or a population – the attitudes, beliefs and concerns that affect vaccine acceptance; and 3) help identify and/or diagnose the factors that influence (e.g., increase or decrease) vaccination confidence to target and evaluate public campaigns and other interventions. V-ABC is a 25-item measure drawing on data from national surveillance efforts to identify key classes of attitudes, beliefs and concerns, and to diagnose and target interventions. .
- In the U.S., similar efforts to design a tiered system of surveys to move from national surveillance into more detailed analysis and diagnosis of specific concerns are underway. In Washington State, for example, Douglas Opel and colleagues have developed a survey of 'Parent Attitudes about Childhood Vaccines' (PACV)-- to identify parents who are hesitant towards childhood vaccines and may under-immunize their child as a result.<sup>22,50</sup> The PACV has been validated and shown to be predictive of under-immunization in the Seattle Group Health population and is currently being tested in other populations. In addition, in collaboration with Dan Kahan, Yale University, an effort is underway to condense the PACV into a five-item survey that would be equally predictive of vaccination behavior. This shortened

survey instrument could be utilized for national surveillance, but requires further testing for validation.

- Robb Butler, from the World Health Organization, presented the Guide to Tailoring Immunization Programmes (TIP) developed by the World Health Organization - EUR in 2013 at the request of the European Technical Advisory Group of Experts on Immunization (ETAGE). TIP is an evidence- and theory- based behavioral insight framework and diagnostic guide to help: 1) identify and prioritize vaccine hesitant populations and subgroups; 2) diagnose the demand and supply –side barriers to vaccination in these populations; and 3) design evidence–informed responses to vaccine hesitancy appropriate to the setting, context and hesitant population. Many factors can influence a parent’s decision to accept immunizations for their child. These factors vary from one location to another, by subgroups within a population, and can also vary with respect to time and specific vaccine. To address vaccine hesitancy effectively, interventions must target specific subgroups and be tailored to address the specific factors that are leading to the vaccine hesitancy at that time and in that context. TIP provides immunization programs guidelines to help in this process of population segmentation, diagnosis of specific concerns and intervention design. TIP has been successfully used in Bulgaria, Sweden and the United Kingdom; however, it does require trained facilitators, which has limited its use beyond these countries. Currently there are plans to make a more practical TIP guide that would require less resources and training.

### **Towards More Sensitive Measures of Vaccination Acceptance: Vaccine Registries and Electronic Health Records**

Immunization Information Systems (IIS) and Electronic Health Records (EHRs) in the U.S. may represent another way to gather information and gain insights regarding vaccination confidence. Both involve the collection of health-related information, including vaccinations, and as such, may provide opportunities to create centralized repositories of community-level coverage data <sup>52</sup> that researchers or public health officials could access to identify groups or places with low vaccination rates. In addition, some states have added coding fields to IIS and EHRs making it possible to determine if there are vaccination delays

or refusals. Information like this can provide the opportunity to quantify how many parents are delaying recommended vaccinations, refusing recommended vaccinations or following an alternative schedule. IIS and EHRs could enhance current national coverage measures as well as be utilized at a state and local level to identify specific “pockets” of under- or unvaccinated children that are often hidden in our current national and state surveillance methods. However, there are still major barriers to implementation of IIS and EHRs, including broader use related to vaccination confidence. Namely, IIS and EHRs are not nationally standardized and vary dramatically from state to state (as well as provider to provider) with regard to widespread adoption and functionality. Despite these challenges, improvement, standardization, and expansion of IIS and EHRs is currently an area of work and attention by several organizations and programs and illustrated by CDC’s IIS Strategic Plan<sup>53</sup> and initiatives such as the Office of the National Coordinator for Health Information Technology (ONC) IIS Data Exchange project<sup>54</sup>

### **Working Group Assessment and Recommendations**

After reviewing the available research, the VCWG concluded that there are many research and monitoring needs when it comes to vaccination confidence and acceptance. First, work is needed on developing and evaluating vaccine and vaccination confidence measures towards the goal of having a set of validated measures. The availability of tested measures will make it possible to evaluate vaccination confidence-related intervention strategies as well as determine best practices. Second, there is a need for a national surveillance system that encompasses both vaccination coverage and vaccination confidence. As is currently possible and done with vaccination coverage, such a system would have the ability to track trends over time; be sensitive enough to detect variations across populations, time, and geography; and provide actionable information regarding vaccination confidence and acceptance.

The VCWG recognized that the state of the science of vaccine confidence and acceptance measurement is a multi-method and multi-national work in progress. With this in mind, the NVAC recommends:

- 1.1 Development of an “index,” composed of a number of individual and social dimensions, to measure vaccine confidence. This index should be capable of 1) a rapid, reliable and valid surveillance of national vaccine confidence; 2) detection and identification of variations in vaccine confidence at the community level; and 3) diagnosis of the key dimensions that affect vaccine confidence.
- 1.2 Continue the use of existing measures for vaccine confidence, including systems that measure vaccine coverage as well as vaccine-related confidence, attitudes and beliefs while the science of understanding and tracking vaccine confidence is being advanced.
- 1.3 The development of measures and methods to analyze the mass media environment and social media conversations to identify topics of concern, to parents, healthcare providers, and members of the public.
- 1.4 That existing approaches and systems for monitoring vaccination coverage and vaccine-related cognitions, attitudes and behaviors be strengthened and enhanced. These include: (1) Immunization Information Systems (IIS) and Electronic Health Records (EHRs) to collect and capture delays and refusals; (2) Reliable and valid measures (or surveys) of cognitive factors, such as adults and parents’ confidence, attitudes and beliefs regarding vaccines and recommended vaccinations; (3) Surveys of provider attitudes and beliefs towards vaccination; and (4) Integration of data from all existing systems to track trends of vaccination confidence over time and to detect variations across time and geography.

### **Strategies to Increase Vaccination Confidence**

The VCWG determined that there is a need to both better identify specific communities where vaccine confidence is low and/or waning (as outlined in the last section) and address those communities with targeted and effective intervention strategies to increase vaccine confidence. The term “communities” here refers to both geographical areas such as cities and neighborhoods as well as population groups that share certain common characteristics or experiences such as ethnicity, race and socioeconomic status among others. The VCWG further concluded that supporting confidence in vaccinations at individual, community and national levels is a complex challenge where no one strategy will be sufficient. Vaccine confidence and the determinants of confidence vary by location,

population, time and vaccine. Therefore, addressing issues of vaccine confidence requires careful assessment of the setting, root causes of lack of confidence and, most likely, the employment of several strategies to increase confidence.

While intervention strategies are needed, currently few studies specifically evaluate the impact of interventions on increasing vaccine confidence.<sup>55</sup> Researchers and organizations working in this area are identifying promising evidence-informed (and in some cases validated) strategies. In addition, the VCWG heard from a variety of presenters working in related and relevant fields such as behavior change, health communication, risk communication and public health promotion, and determined there were many strategies that could be adapted for use to increase vaccine confidence. However, as outlined in this report, the study of vaccine confidence is a relatively new field with definitions and clear measures still being determined. Therefore, intervention strategies aimed to increase confidence in vaccinations are also developing. Highlighted throughout the VCWG recommendations are the need for continued research towards development of validated interventions and the need for accessible repositories where strategies, resources and effective practices can be shared to facilitate communication and forward progress amongst those working in this field.

The VCWG drew upon the published research, invited presentations, and the online focus group discussions in the development of their recommendations. These recommendations are presented below as three general categories of strategies to support and increase vaccine confidence:

1. Communication and Community;
2. Healthcare Providers; and
3. Policy

## **Communication and Community Strategies to Increase Vaccine Confidence**

2.1 NVAC recommends healthcare providers, immunization programs, and those involved in promoting recommended vaccinations actively reinforce that vaccination of children according to the ACIP recommended schedule is the social norm and not the exception. Misperceptions that vaccination in line with the ACIP recommended schedule is not the norm should be appropriately addressed.

The vast majority of parents in the U.S. choose to vaccinate their children in accordance with the ACIP recommended schedule. Numerous presenters stressed the importance of promoting public awareness that vaccination is the social norm. While the data continue to show that coverage rates are high, stories and rhetoric in the media and elsewhere can lead people to believe vaccination rates are much lower than they are. Communicating that 80-90 percent or more of parents choose to vaccinate their children in line with the recommended schedule not only ensures that parents and the public have access to accurate information, but can serve to strengthen this social norm by reinforcing to parents and the broader community that their decisions to vaccinate are in agreement with the values and decisions of most parents.

2.2 NVAC recommends consistent communications assessment and feedback pertaining to vaccine confidence. These include:

2.2.1 Creation of a Communication Assessment Infrastructure to assess vaccine sentiment and provide timely, accurate and actionable information related to vaccination confidence and acceptance to relevant stakeholders. This system should have the capability to regularly assess vaccine-related messaging environment (e.g., to identify new or emerging concerns and questions) to assess understanding and effectiveness of population education and information materials and resources.

2.2.2 Identification, evaluation and validation of communication resources and approaches in terms of their effects on enhancing vaccine and vaccination confidence so that effective (“evidence-based/evidence-informed”) interventions and best practices can be shared and more widely used.

2.2.3 Creation of a repository of evidenced-based best practices for informing, educating and communicating with parents and others in ways that foster or increase vaccine or vaccination confidence. This repository would be maintained and expanded as future evidence is compiled regarding messages, materials, and interventions that positively affect vaccine or vaccination confidence.

The most effective communication strategies are typically those tailored or customized to the specific questions and concerns of a particular target audience. This requires ongoing assessment of current and arising vaccination sentiments. Towards this aim, the NVAC recommends the creation of a dashboard to follow the vaccine-related messaging environment and the attitudes, questions and beliefs regarding vaccinations. This will help to both tailor messages and also assess whether those messages are having an impact on addressing questions and concerns and increasing vaccine confidence.

Effective communication also requires understanding which messages are most effective for different audiences. This is not always straightforward. It has been shown that the effectiveness of messages often varies depending on how confident parents are with respect to vaccines and that some pro-vaccine messages can have unintended consequences, especially with those most hesitant about vaccination.<sup>56</sup> As a result, the VCWG also recommends continued evaluation of communication resources and approaches with a variety of audiences. Specifically for vaccinations, message testing following segmentation of parents according to vaccination confidence is of critical importance to increasing our understanding of how best to communicate with all parents regarding vaccines.

Finally, to facilitate the translation of research into practice, the VCWG identified a need to create a repository of evidenced-based best practices. This would provide researchers and public health workers a database of the most current data, materials, and resources related to vaccine and vaccination confidence. It would also facilitate coordination and collaboration on strategies and approaches to foster, build or maintain vaccination confidence, including ones focused on testing and evaluating communication strategies across diverse settings and populations.

2.3 NVAC recommends the development of systems to support parent and community efforts that seek to promote vaccine confidence and vaccination.

Parents themselves can often be the strongest and most persuasive advocates for vaccination in their communities. As trusted members of their communities and with a direct understanding of the concerns of their peers, parents who support vaccinations can serve as powerful partners for public health by identifying and helping to address the most relevant issues. While the vast majority of parents choose to vaccinate their children, this majority is often not the most vocal or visible. Seeing an opportunity to help give a voice to this majority, several organizations and immunization programs have partnered with and provided resources and support for parents looking to communicate about the importance of vaccination in protecting their children and their community. The NVAC recommends continued support for parent and community-based efforts.

2.4 NVAC recommends support for a community of practice or network of stakeholders who are actively taking steps to foster or grow vaccine confidence and vaccination; such a network can foster partnerships and encourage sharing of resources and best practices.

There are many stakeholders, healthcare providers and public health advocates who are working to promote childhood vaccinations at a local, state or national level. The NVAC believes that efforts to foster collaboration and share information would bring many benefits, including helping stakeholders find useful resources, building a portfolio of effective practices, and fostering better understanding of the determinants and factors associated with vaccine confidence.

### **Healthcare Provider Strategies to Increase Vaccine Confidence**

Providers are consistently cited as a key factor in parent vaccine decision making<sup>14,35,57</sup>.

Therefore, providers, including pharmacists, nursing professionals, physicians, and other health staff involved in vaccination need to be equipped with the resources and materials needed to address parent questions and concerns – and be confident in their ability to do so. Confident, well-informed healthcare providers who can effectively communicate to the public and patients about the benefits of immunization are central to achieving optimal health outcomes. Provider confidence means that clinical staff should feel they have



sufficient time to spend with parents or patients to answer questions about vaccinations, accurate and up-to-date information about the recommended immunizations, and the skills and resources needed to effectively communicate with concerned parents. For these reasons, the NVAC believes it is important to put a high priority on ensuring adequate support, resources and training for healthcare providers.

3.1 NVAC recommends the development and deployment of evidence-based materials and toolkits for providers to address parent questions and concerns. These materials and toolkits should continue to be revised to incorporate the latest science and research.

3.1.1 A repository of evidence-based effective practices for providers should be an output of this effort.

There is a need to provide evidence-based communication strategies, resources and other interventions that can be used to address, build or foster vaccine and vaccination confidence in patients and providers. Immunization intervention and communication strategies that healthcare providers can tailor to the specific characteristics or needs of their patient or parent population are in particular demand. While there are toolkits and other vaccine-related education resources currently available, the NVAC VCWG heard from healthcare providers that most of these toolkits have not been evaluated or validated. In addition, there is ongoing discussion and research to establish what the most effective communication strategies are for providers in both initiating and engaging in conversations about vaccinations. There are several promising strategies currently being tested to address these issues, but still need further study and validation across different populations and with parents segmented by their confidence in vaccines.<sup>58,59</sup>

The NVAC also recommends the establishment of a repository for this information, which is easily accessible to a range of providers (e.g., on on-line or web-based repository). Once effective intervention and communication strategies and resources are developed and reviewed, this information should be disseminated and readily available to a wide range of immunizers.

3.2 NVAC recommends curriculum and communication training that focuses on vaccine confidence (e.g., strategies and approaches for establishing or building confidence) be developed and made available for healthcare providers, including doctors, nurses, alternative providers and ancillary care providers.

3.2.1 This training should encompass “providers-in-training,” such as students, residents and interns as well as currently practicing physicians, nurses and other healthcare providers through Continuing Medical Education (CMEs).

3.2.2 Clear and accessible information on vaccinations, the schedule and any changes to the immunization schedule should be developed specifically for providers and made available to them through resources they utilize most.

Training healthcare providers to communicate effectively about vaccines is a critical task in the effort to increase vaccine confidence. Focusing effort on the education of healthcare students is one strategy to ensure that providers are knowledgeable and confident in vaccines and vaccination recommendations, and confident in negotiating potentially complex conversations with their patients. Educating students to this end will require the development of curricula that meet the needs of the provider once in practice. In addition, vaccine education and communication-related curricula should be developed for student nurses, physicians, interns, and healthcare providers, and should be applicable to the populations and environments in which they work. As continuing education for all healthcare providers is a necessity throughout the career-span, educational information should also be available to practicing providers in formats that are easy to access and available from sources they trust and use. CMEs are one method to reach current providers along with workshops at annual meetings and conferences.

3.3 NVAC recommends the development of: (i) Provisional billing codes for vaccine counseling when vaccination is ultimately not given; and (ii) Pay for performance initiatives and incentives as measured by: (a) Establishment of an immunizing standard within a practice; and (b) Continued improvement in immunization coverage rates within a provider’s practice.

In order to help address provider concerns regarding the amount of time that may need to be spent with some parents to educate them about the benefits of vaccines and address concerns, billing codes specific to immunization counseling should be established. Providers want to take the time to engage and answer all questions parents may have with respect to vaccination. In general, the current billing codes, which require vaccination administration, are sufficient as the reimbursement also includes counseling time. However, there is currently no billing code available to reimburse providers for time taken to address the questions and concerns of parents who ultimately choose not to vaccinate. While parents may refuse vaccinations at one visit, the time and conversation they had with their child's healthcare provider may encourage them to vaccinate at a later date. This highlights the value of these conversations and provides justification for billing codes to adequately compensate providers for their time and services. To achieve high immunization practice standards in clinical settings, formal recognition of the investment of time made by providers in addressing parent or patient questions and concerns is critical. Billing codes for immunization counseling could provide the additional benefit of allowing the establishment of performance incentives for providers, and allowing providers to gauge how they are performing when taking time to explain the risks and benefits of vaccination to parents or patients. This recommendation is aimed at addressing concerns and issues related to immunization counseling when vaccines are not administered. The NVAC believes that the impact of this recommendation should be evaluated as more data on the effectiveness of billing for counseling without immunization administration become available.

## **Policy Strategies to Increase Vaccine Confidence**

4.1 NVAC recommends states and territories with existing personal belief exemption policies should assess their policies to assure that exemptions are only available after appropriate parent education and acknowledgement of the associated risks of not vaccinating, to their child and community. Policies that do not do this should be strengthened.

4.1.1 Increased efforts should be made to educate the public and state legislatures on the safety and value of vaccines, the importance of recommended vaccinations and the

ACIP schedule, and the risks posed by low or under-vaccination in communities and schools.

As outlined earlier in this report, all states in the U.S. require children to receive a number of vaccines prior to entering school. School and day care vaccination requirements have been shown to effectively increase vaccine coverage and provide an important public health benefit by reducing rates of vaccine-preventable diseases.<sup>36</sup> All fifty states and the District of Columbia permit medical exemptions, which protect children where vaccination is medically contraindicated. Almost all states allow non-medical exemptions for religious beliefs and many states allow exemptions for personal beliefs. As of July 2012, forty-eight states allowed religious exemptions, and eighteen allowed exemptions based on philosophical or personal beliefs.<sup>60</sup>

Steps required for obtaining exemptions vary across states. Some state policies make exemptions relatively easy to obtain while others are more difficult and require parents to receive education on the risks and benefits of vaccination from a licensed healthcare provider. Research has demonstrated that there is a relationship between the ease of exemption and the exemption rate. States with less rigorous procedures for obtaining exemptions have higher exemption rates.<sup>15,61</sup>

Exempt children are at increased risk for acquiring vaccine-preventable diseases and pose a risk for transmitting infection to other susceptible people in their communities.<sup>37</sup> The risk is also amplified because children with personal belief exemptions are often geographically clustered. Data show that these geographic areas with high rates of vaccination exemptions have higher rates of vaccine-preventable diseases.<sup>37</sup>

For the reasons outlined above, the NVAC concluded that exemptions should not be allowed to easily occur because of misinformation or convenience. Exemptions, like immunizations, carry responsibilities that need to be recognized by state legislatures and the public. Therefore, the NVAC recommends that states with personal beliefs exemption policies ensure parents seeking exemptions first obtain education from a state approved 'appropriate' source as well as explicitly acknowledge the risks associated with not receiving recommended vaccinations. The NVAC recommends 'appropriate' sources be

state health departments or healthcare providers for children, whom the state considers appropriate for immunization education. The VCWG further recommends that state legislatures should be informed of the individual and public health benefits vaccines provide along with the risks associated with not vaccinating (e.g., more children susceptible to vaccine preventable diseases).

4.2 NVAC recommends information on vaccination rates, vaccination exemptions and other preventative health measures (e.g., whether a school has a school nurse, etc.) for an educational institution be made available to parents.

4.2.1 Encourage educational institutions and childcare facilities to report vaccination rates publicly (e.g., via a school health grade or report).

When choosing a school for their child, parents often seek out and have access to a range of information from school performance indicators and student test scores to after school programs to policies to ensure the safety and health of their child. As stated above, communities with higher rates of exemptions have higher rates of vaccine-preventable diseases. The VCWG concluded, given this fact, many parents would be interested to know the vaccination rate at their child's or children's school. While this information is likely collected by state health departments, it is often not easily accessible to parents. The VCWG therefore recommends schools make this information readily available to parents so that they can be informed when it comes to decisions regarding the safety of their children.

4.3 NVAC recommends "on-time vaccination" should be included as a Quality Measure for all health plans, public and private as a first line indicator of vaccine confidence. NVAC acknowledges that other issues, such as access, can also effect on time vaccination.

### **Continued Monitoring of the State of Vaccine Confidence**

The NVAC also believes that it is important to continue monitoring and evaluating the state of vaccine and vaccination confidence in the US. Tracking this on a regular basis will keep the NVAC and other stakeholders informed about what is being done to implement these recommendations.

5.1 The NVAC recommends that the National Vaccine Program Office (NVPO) should work with federal and non-federal partners to develop an implementation plan to address vaccine confidence, including metrics, and report back to NVAC on progress, annually.

DRAFT

## Conclusion

As this report indicates, sustaining, and in some cases, improving timely acceptance of recommended vaccines and vaccinations for children depends on the active involvement of a range of practitioners and parents among others. At the heart of these efforts are relationships, with the strongest and most effective relationships being those built on trust. Vaccine confidence encompasses these important concepts – it recognizes that parents and healthcare providers need to have trust in the recommended vaccines, trust in the providers who recommend and administer vaccinations, and trust in the processes that lead to vaccine licensure and the recommended schedule.

In looking at the current state of affairs in the United States, the NVAC found much that is positive or encouraging. First, childhood immunization rates are at or near historically high levels. The vast majority of parents are following the ACIP recommended immunization schedule, and the vast majority of children are receiving recommended vaccines – and getting them on time. While vaccine coverage rates are an incomplete measure of vaccine confidence, the fact that acceptance is high does indicate most parents have confidence in recommended vaccines. Importantly, and in line with the recommendations of experts, efforts are made by the CDC and others to highlight and promote this social norm for children so other parents, especially first-time parents, can be confident in their decision to follow the ACIP schedule. NVAC recognizes the importance of these efforts and recommends that those involved in promoting recommended vaccinations continue to actively highlight that following the childhood schedule is the social norm and not the exception. It is also recommended parents and the community at large, be able to know the vaccination rates and vaccination exemptions in the community, but especially in educational institutions (e.g., day care, elementary, middle and high schools).

It was also encouraging that most parents seek, and trust, information and guidance from healthcare providers when it comes to vaccines and vaccinations. Most healthcare providers recognize the important roles they play in fostering confidence and acceptance of recommended vaccines. While many are encountering families or parents who are considering delaying or foregoing recommended vaccinations, the vast majority of

healthcare providers are willing to engage in lengthy vaccine-related conversations and take steps that foster confidence, and ultimately, acceptance, but are seeking assistance on how to conduct these conversations most effectively and efficiently.

The NVAC VCWG's examination of the state of vaccine confidence did, however, find a number of areas where improvement or additional efforts are needed. The first involves measurement and assessment. While the CDC's National Immunization Survey is a powerful and important tool for monitoring national and state immunization coverage, there is no system or survey that routinely monitors vaccine confidence or the factors related to confidence. There is a need for regular as well as better metrics to track parents' vaccine-related confidence and to provide timely, accurate, tested, and actionable information to relevant stakeholders. It is also important that tracking and intervention efforts go beyond the national and state levels. Given vaccine preventable disease outbreaks begin in communities, including in schools, efforts are needed to find ways to assess vaccine confidence at the community, and perhaps healthcare provider, levels. Further, and as noted in this report, the state of science of vaccine confidence and acceptance measurement will involve using multiple methods and approaches, including looking at efforts in other countries.

Related to the above, there is also a need for research and evaluations that can identify evidence-based interventions related to fostering vaccine confidence. Relatively little is currently known regarding the best and most effective approaches to respond to parents who lack confidence in recommended vaccines, how to interact with communities that lack confidence, or what actions to take to address low or declining vaccine confidence. Based on experience to date, it is likely these efforts will be multidisciplinary.

While the Working Group discovered that excellent work is being done on the communication front, this is another area where needs and opportunities exist. The needs include having consistent and regular assessments of the vaccine communication environment. It is important for policy makers, immunization programs and healthcare providers to have information on parents' vaccine-related knowledge, beliefs, intentions, questions, concerns and confidence. It will also be helpful to know whether vaccine



education efforts and materials are addressing the right questions and concerns and building vaccine confidence, suggesting continuous tracking and evaluation. In addition, developing a repository of evidence-based or evaluated approaches and materials would greatly assist immunization programs and healthcare providers. Evidence-based approaches and materials can increase both the effectiveness and efficiency of communication and education efforts.

Finally, going forward, it is important to support front-line healthcare providers in their daily efforts to educate, inform, and guide parents on vaccines and vaccination recommendations. Healthcare providers are consistently cited as a key factor in parent vaccine decision making – parents usually follow the recommendations of trusted healthcare providers. Today, and likely in the future, there are many demands on healthcare providers' time and their expertise is sought on many topics. As such, a high priority needs to be placed on 1) training and assisting healthcare providers on vaccines and vaccine communication so they can effectively address parent questions and concerns (e.g., through curriculum, coaching, regular updates on vaccine recommendations and vaccine safety, a repository of evidence-based education materials) and 2) systems and incentives that recognize the value of healthcare provider-parent vaccine education and offer encouragement for undertaking such efforts (e.g., being able to take the time to address parents' concerns and to be able to bill for vaccine-related counseling).

The National Vaccine Advisory Committee thanks the Assistant Secretary for Health and Human Services, and the National Vaccine Program Office, for extending the invitation to examine the state of vaccine confidence in the United States. Vaccines have made an enormous contribution to the health and well-being of all, but there are still some who question or doubt their value and importance. It is thus essential to recognize that confidence now plays a central role in vaccine acceptance – and investments and efforts are needed to ensure high levels of trust exist in recommended vaccines, healthcare workers who provide them, and entities and processes involved in vaccination policies and recommendations.

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## **Appendix A: Working Group Membership**

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Michael Bartholomew, IHS

### **HHS NVPO Staff and Technical Advisors:**

Bruce Gellin, NVAC Executive Secretary

Sharon Bergquist

Glen Nowak

Katy Seib

Judith Mendel

Jaime Earnest



## **Appendix B: Working Group Agenda**

### **Epidemiology, Measurement, and Tracking**

1. Coverage data and attitudes and beliefs surveys: CDC (Kristine Sheedy, Allison Fisher, and Glen Nowak).
2. Predictive vaccine confidence surveys and other methods to track vaccination confidence: Douglas Opel, Nicolas Sevdalis, and Saad Omer.

### **Perspectives**

3. Healthcare providers: American Academy of Pediatrics (Kathryn Edwards).
4. State and City health workers: AIM (Katelyn Wells), NACCHO (Paul Etkind) and ASTHO (Kimberly Martin).
5. WHO SAGE Working Group on Vaccine Hesitancy: Bruce Gellin and Heidi Larson.
6. Nurses: Melody Ann Butler.
7. Parents: Three parent focus groups.

### **Strategies to Support Vaccine Confidence**

8. Communication strategies: Dan Kahan.
9. Health communication and social/news media: Ivan Oransky, Joseph Cappella, and Rumi Chunara.
10. National strategies for surveillance and engagement: Julie Leask.
11. Provider reimbursement and opportunities to support provider-patient conversations: LJ Tan.
12. Lessons from anti-tobacco campaigns: Ann Aikin.
13. Community mobilization: WHO (Robb Butler) and Vax NW (Mackenzie Melton and Todd Faubion).
14. Decision making and risk analysis: Cornelia Betsch.